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ABSTRACT

A questionnaire designed to provide parents of children with specific learning disabilities with an opportunity to react to and evaluate the diagnostic and counseling process experienced with physicians, psychologists, and educators was returned by 125 parents. Among results of the study covering child background information, parent background information, professional contact information, and recommendations to professionals were that parents recommend the use of terminology they can understand and that they request the inclusion of both parents in conferences and meetings. (IM)

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WHAT PARENTS OF THE LEARNING DISABLED REALLY WANT TO GET FROM PROFESSIONALS:

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WHAT PARENTS OF THE LEARNING DISABLED
REALLY WANT TO GET FROM PROFESSIONALS:

A major focus in the preparation of personnel in the child-care professions centers on relating to parents. One source of information for understanding these relationships can be found in literature related to the parent counseling process (Noland, 1970, 1971; Hewitt, 1970; Schild, 1971; Wolfensberger, 1967; Dembinski and Mauser, 1973). Within that specific body of information, a series of recommendations has been offered on how to relate to parents of educationally handicapped children. The information inevitably includes a discussion of deficits or inadequacies in the parents of the handicapped child. The reader given a series of strategies, techniques, or theoretical overviews as to why parents may or may not respond to professional advice. These recommendations appear to be somewhat biased against parents. It is apparent that professional people have a channel by which to express their experiences and observations. Parents, on the other hand, have no such mechanism available to them. It is for this specific reason that this study was conducted.

Purpose of the Study

The purpose of this study was to provide parents of children with specific learning disabilities with an opportunity to react and evaluate the diagnostic and counseling process that they experience in relation to three distinct groups of professional people, i.e., physicians, psychologists, and educators.

Description of the Questionnaire

The questionnaire consists of four sections: 1) Child Background Information, 2) Parent Background Information, 3) Professional Contact Information, and 4) Recommendations to Professionals.

The Child Background Information section provides an overview of a particular child's characteristics, e.g., age, sex, disability, and treatment received. Parent Background Information yields demographic and biographic information related to the parents of the child. The Professional Contact Information section focuses on the crucial elements of this particular study. In this section parents have an opportunity: 1) to provide information related to how long they have been aware of the child's disability; 2) to indicate their reaction to the diagnosis; 3) to indicate whether or not they returned to the professional who originally confirmed the diagnosis; 4) to cite any reasons for seeking additional opinions if they were sought; and 5) to indicate their reactions to those opinions. Recommendations to Professionals is the crucial section of the questionnaire. In this section the parents have the opportunity to rank some traditional role behaviors ascribed to physicians, psychologists and teachers in terms of their relevance to their child's disability. Parents were asked to rank the behaviors as Important, Not Important, or Does Not Apply.

Results of the Study

I. Summary of Child Background Information

A Total of 125 questionnaires were returned from parents having children

with specific learning disabilities. This represents slightly more than a 40 percent return rate on a mail survey. The authors consider this an above average response rate. The 125 questionnaires included information on 84 males and 38 females.

The range of services being provided is as follows: 19 of the children are receiving no services; 29 are enrolled full-time in a public school education class; 11 children are enrolled on a part-time basis; 4 children are in a public special school; 33 are in a private school; 40 children are in a regular class but are receiving special help; 6 of the children are in private residential facilities; 5 are involved in community clinics; 23 are receiving regular medical treatment; 9 of the children are in a regular school receiving no extra assistance; 2 are involved in counseling programs. Of the 125 respondents, 111 of these represent natural children; 1 a stepchild, 1 a foster child; and 12 represent adopted children with specific learning disabilities.

II. Summary of Parent Background Information

Approximately 80 percent of the parents of learning disabled children are between the ages of 30 and 49. Ninety-five percent of the families reporting indicated they were married. Over 83 percent of the respondents indicated they were living in a suburban or an inner-city area.

III. Summary of Professional Contact Information

Almost two-thirds of the parents with learning disabled children indicated that they were aware of their child's learning problem prior to or shortly after his entrance into school. Confirmation of the parent's suspicions regarding their child's problem was obtained essentially from three major professional people: physicians, psychologists, and teachers. Interestingly enough, most of the parents indicated that when informed of the diagnosis, they felt accepting, relieved, but yet frustrated. Approximately 10 percent of the parents indicated that they felt in any way shocked, guilty, angry or were disbelieving. The appearance of the professional person was described by the parents as being understanding and knowledgeable. Very few parents described professionals in negative terms, e.g., insulting, nervous, rude, evasive, etc. Over 90 percent of the parents who sought the advice of another professional; the majority reported that they wanted a confirmation of the first diagnosis in addition to another opinion regarding the possibilities for treatment. The second professional person consulted was also described by parents as courteous, informative, helpful, and understanding. In general, all responded in positive terms. Up to a third of the parents described themselves as feeling awkward, nervous, and to some extent, like they were imposing on the professional when they questioned him.

IV. Recommendations to Professionals

The following <u>recommendations to physicians</u> were listed by parents in terms of their decreasing order of importance:

1. Use terminology we can understand.
2. Allow us to ask questions.
3. Tell us diagnosis as soon as it is known.
4. If you are not interested in treating our child, refer us to someone who may be.

5. Give us materials to read
6. Be willing to discuss our child's problems with his/her teacher.
7. Require both parents to discuss their concerns with you.
8. Tell us about health problems our child may experience.
9. Give the parents copies of reports.
10. Give us your opinion about how well our child will learn in school.
11. Give us the opportunity to call for advice--a hot line service.
12. Give us more child rearing ideas (feeding, toilet training, etc.).
13. Tell us if we should place our child somewhere outside the home.
14. Do not tell us the diagnosis if you feel it will upset us.

The following recommendations were offered by parents to psychologists. The recommendations are listed in decreasing order of importance:

1. Use terminology we can understand.
2. Require both parents to discuss their concerns with you.
3. Give us materials to read.
4. Give us copies of reports.
5. Tell us how to discipline our child
6. Tell us what our other children might think about our handicapped child.
7. Tell us what to do when our child throws a tantrum.
8. Tell us our child's I.Q.
9. Tell us how to explain sex and drugs to our child.
10. Suggest toys our children can play with
11. Tell us what to say to our neighbors.

The following recommendations, listed in decreasing order of importance were offered by parents to teachers:

1. Tell us how our child gets along with others in class.
2. Tell us if our child gets in trouble.
3. Show us how to teach things to our child
4. Use terminology we can understand.
5. Tell us what you expect our child to learn.
6. Require us to attend parent conferences.
7. Give us materials to read.
8. Be willing to discuss our child's problems with our doctor.
9. Tell us if you think our child has progressed as far as he possibly can.
10. Tell us what types of jobs our child could hold.

Summary of Recommendations to Professionals

Analysis of the data on Recommendations to Professionals indicates the following:

1. Parents agree more on their recommendations to teachers than they do on their recommendations to physicians and psychologists.

2. The inclusion of both parents in any conference or meeting is very important.

3. The provision of reading material is high on the list of priorities.

4. Parents strongly encourage receiving copies of reports written about their children.

5. Parents emphasize the need for interdisciplinary communication.

6. There is an emphasis on immediate relevant advice, e.g., how to teach children to do certain things, how to manage tantrums, etc., as opposed to offering long term recommendations regarding future educational or vocational outcomes.

These results indicate that parents are requesting an honest evaluation of their child's problem and capabilities. Literature regarding parent counseling indicates that parents sometimes have a difficult time accepting the reality of a child's problem. The parents' inability to accept a diagnosis is sometimes cited as a reason for evasiveness, feelings of guilt, rejections, and agency shopping, etc. It would appear that, even though this kind of reaction in parents does occur, parents express the point of view that they do want to confront a problem directly. If this proves to be the case, then these findings have some interesting implications for parent counseling programs.

These results, though tentative, seem to indicate that parents do have a definite opinion regarding their experiences with professional people. The preliminary findings indicate to us that professionals might re-evaluate their present strategies in dealing with parents of exceptional children. This re-evaluation should include: (a) a de-emphasis on the use of professional jargon or terminology; (b) discussions of realistic day-to-day life management techniques; (c) providing the rationale for conclusions made about a child; and (d) avoidance of long term predictions which may or may not be realized.

REFERENCES

Dembinski, R.J., & Mauser, A.J. "Parental Perceptions of Diagnostic and Counseling Procedures Used by Physicians, Psychologists, and Teachers." Proceedings of the International Symposium on Learning Disabilities, III, Indianapolis, Ind: National Rehabilitiation Training Institute, 1973.

Hewitt, S., Newson, E. & Newson, J. The Family and the Handicapped Child. Chicago: Aldine Publishing Co., 1970.

Noland, R.L. Counseling Parents of the Ill and the Handicapped. Springfield Ill.: C.C. Thomas Publisher, 1971.

Noland, R.L. Counseling Parents of the Mentally Retarded. Springfield, Ill.: C. C. Thomas Publisher, 1970.

Schild, S. "The Family of the Retarded Child." In Koch, R. and Dobson, J.C. (eds.) The Mentally Retarded Child and His Family, New York: Brunner-Mazel Publishers, 1971, 431-442.

Wolfensberger, W. "Counseling the Parents of the Retarded." In Baumeister, A.A. (ed.) Mental Retardation. Chicago: Aldine Publishing Co., 1967, 329-400

*Selected Convention Proceedings--International Conference--ACLD. Houston, Texas--February, 1974

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